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Research article

Growing up with confidence: using telehealth to support continence self-care deficits amongst young people with complex needs

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ABSTRACT

Background Many young people with chronic ill health use technology for self-care activities, but little is known about the use of telehealth amongst those with spina bifida. The limited availability of specialist continence nurses in primary care settings, for this client group in the UK, exacerbates their reliance on parents or carers.

Objectives

1. Exploring the way in which home-based and technology-enabled clinical interventions affect young people's engagement in continence self-care.
2. Articulating the way in which telehealth impacts on nursing practice and the conduct of remote clinical encounters.

Methods A virtual nurse-led clinic was established to support a small cohort of service users and their parents from home. Data from participants were collected and analysed alongside a narrative record of a reflective diary, used by the continence specialist nurse.

Results Participants reported increased level of self-confidence, which was attributed to interacting remotely with the specialist nurse. The virtual clinic assisted users to attain some self-care goals as well as assert their role as partners in care planning. The specialist nurse gained new valuable skills in mastering telehealth technology and managing remote clinical provision.

Conclusions Using Skype™ to support young people with complex needs is an effective intervention to support continence care at home. Dedicated technical support during the initial set-up phase and on-going clinical mentorship are needed to ensure that telehealth is successfully embedded within health care practice.

Keywords: adolescents, continence, nursing, telehealth

What this paper adds?

- Young people with complex care needs can benefit from using telehealth as the digital gateway for successful therapeutic interaction. For some, this is a preferred mode of communication, which enhances their sense of control and supports self-care goal attainment.

- Nursing staff in small primary care organisations are well situated to drive technological innovation if given the right support and training from the outset.
- Skype™ is a simple and cost-effective tool to support virtual clinics, taking advantage of the pervasiveness of technology and the Internet in most homes.

INTRODUCTION

A large proportion of young people with spina bifida (SB) experience bladder and bowel incontinence,¹ with an associated negative impact on their expressed quality of life.² Medical and surgical interventions are often used to alleviate physiological symptoms associated with the condition. Behavioural interventions are also needed to support those who may experience problems with memory and difficulty in initiating self-care and those who may lack motivation.³ Working closely with service users of the Scottish Spina Bifida Association (SSBA), we know that despite the excellent provision of paediatric services in acute settings, very little is offered and delivered to young people in primary care and community-based clinics. To address this service gap, the SSBA offers access to a continence nurse specialist who is based in our headquarters in the west of Scotland. To extend the availability of the service, to users from across the country, we decided to explore whether telehealth could enhance our outreach capacity and entice young people to engage with the new provision of a home-based virtual service.

Telehealth is used across the globe to support an array of health care services and to deliver interventions for a wide range of conditions. An encompassing definition offered by the Royal College of Nursing (UK) (http://www.rcn.org.uk/development/practice/e-health/telehealth_and_telecare) suggests that telehealth includes remote monitoring of physiological data and the use of information and communication technologies for remote consultations. Such an interaction may be between health professionals or between a health professional and a patient or a service user. The literature identifies a wide range of telehealth services that specifically aimed at catering for clinical needs of young people and their families. These include remote therapy for eating disorders⁴ telepsychiatry consultations,⁵ supporting victims of sexual abuse,⁶ palliative care provision at home⁷ and health screening,⁸ to note but a few.

METHOD

The literature review we conducted was focused on two strands: articles that described telehealth projects involving young people, and studies that focused on continence care for adolescents with SB. The overall conclusion from reviewing telehealth literature was succinctly summarised by Lee et al.⁹ who asserted that the main challenge to using telehealth is the lack of robust evidence for the efficacy of the technology in general. Our review also highlighted that very little is known about the use of telehealth to support the holistic needs of young people with SB and their continence care. The small size of the population, the intimate nature of continence care and the social 'taboo' concerning this subject may explain the

lack of published studies. However, literature concerning telepsychiatry and remote palliative care for children at home was used as a 'proxy' knowledge source to inform our approach.

Following the literature review, the nursing team refined the inclusion criteria for the study, agreed a new clinical pathway for the proposed virtual clinic and identified potential participants between the ages of 12 and 18 years on our database of service users. Candidates had to be dependent on 'others' for continence care, to have good dexterity and to be able to give an informed consent to take part in the study. A total of 25 potential service users were identified, and an information pack was sent to the families. Prior to engaging with service users, we followed the internal ethics approval process, developed to ensure that service users are not subjected to any harm and that their rights are preserved and enhanced.

Fifteen families asked for further information, and a face-to-face meeting was held with those who wanted to take part ($n = 11$) in the study. This first meeting was an opportunity to set care goals, agree a course of action and confirm technical requirements. A short questionnaire, informed by best practice approach to engaging young people in evaluating participation work (<http://www.participationworks.org.uk/resources/evaluating-participation-work-the-toolkit-and-the-guide>), was given to the final 10 participants, to capture baseline measurement and compare results at the end of the study.

We ensured families had access to Skype™ and offered assistance in installing the software on their own computer, so it could be used from home. The quality and convenience of this low-cost product had to be assessed against risks such as safety and confidentiality of sensitive health care data. Clinical effectiveness was also explored by piloting a simulated clinical case study, reviewing a few case reports and exploring commercial health care organisations that offer services in a similar fashion (https://onlinedoctor.lloydspharmacy.com/talk-to-a-private-gp/vc/video_conference_with_a_private_gp). Overall, Skype™ was deemed as a secure way of communicating, where information is encrypted and digital certificates are used to authenticate users. No special firewall rules were needed for Skype™ to function on a personal computer (PC) or a mobile device, connected to a broadband from home.

The virtual clinic was held in the evening and families were given a weekly 15-min session each. The specialist nurse was available to explore progress with agreed care plan and offer guidance and support to both young people and their parents, if needed. Each family made its own arrangements for where in the house the consultation would take place, but a headset was provided to ensure that confidential advice could be offered. Prior to the consultation, the nurse and the young person would confirm the time of the session via a text

message. After each session, the service user was asked to complete a printed evaluation form, sent as part of a welcome pack in the mail. The continence nurse kept a reflective diary where rich qualitative data were captured for evaluation and clinical supervision purposes.

RESULTS

The use of Skype™ proved to be a reliable and robust mechanism to engage in remote clinical encounters for our service users. In time and through increased usage, most minor user errors and connection problems were resolved and the quality of the output, in terms of sound and images, was good enough for effective interaction. Only one Skype™ session had to be terminated, and the clinical encounter continued using a phone on a landline. Some problems were encountered with PCs and home-based broadband, but these were not related to the software. A few participants noted they had some concerns using Skype™, as it was not similar to Facebook™, which they were most familiar with. A few who were new to using Skype™ were persuaded, through their positive experience with the technology, to continue and use the product for their own social interactions with peers and family.

Interestingly, the nurse who was new to Skype™ herself mastered the tool quickly and efficiently and was able to offer participants advice on dealing with minor technical challenges during the consultation. She was able to competently take on the role of a 'trouble shooter', whilst noting in her diary that she was 'terrified' of using Skype™ at the outset of the study. This change in confidence was also very evident in a few participants who deliberately excluded themselves from view in the first few virtual clinics. Noticeably, over a period of nine weeks, one young person who would first be present in the room but unseen joined the parent on camera and took more of an active role in the discussion. She then led the discussion, whilst her parent remained in the room, but unseen, and then asked for an individual consultation without the parent being with her at all. The transformation in the way participants conducted themselves when dealing with the specialist nurse was also noted by colleagues who care for these youngsters as NHS patients.

The baseline data captured from young people themselves suggested that most of them perceived their health status in terms of being 'happy' and 'well'. When asked to indicate their level of dependency on others, many were only 'sometimes' independent or not independent at all prior to enrolling in the study. They all needed 'a lot' of help with their bowel care, and the majority needed some help with bladder care too. A few highlighted their disability (bound to wheel chair or having epilepsy) as a hindering factor to gaining independence at home or outside the house. They all had on-going contact with specialist NHS staff, in paediatric outpatient settings, on regular but infrequent occasions. Efforts to gain written data after each clinical session proved unsuccessful. Despite a reminder at the end of each session to complete the evaluation form and send it in the self-addressed envelope back to the nursing team at the SSBA, only half of the original cohort completed our survey

at the end of the study, noting they still need help with continence care but omitting to mention the change they perceive in their ability to perform self-care tasks. Noting the gap in comparative data, the nursing team decided to conduct a short telephone interview with those participants who attended the virtual clinic during the entire duration of the study ($n = 6$).

The results suggest that young people and their families valued the continuity of care and the frequent interaction with a specialist professional. Young people appreciated the fact that they did not have to be taken to the clinic by parents, and parents themselves appreciated the timing of the clinic. Being in the evening meant they did not have to take time off work or take their child off school, which often is the case with regular attendance in outpatient departments. One participant suggested that Skype™ gave her the option of seeing what the face of the nurse is saying. She went on to say she felt '...less under pressure than being at a clinic, I don't have to worry I'm going to get pounced on for bloods etc...'. Another stated he is '... happy to discuss personal things over this (Skype™) but not face to face...'. Others said '...I feel more confident, speaking to a nurse on my own about personal things, without my mum being present...' and '...Yes I'm glad I took part ... The advice and what I can do have helped my confidence... I'm not so shy now with other nurses...'.

Reviewing the qualitative data within the reflective diary compiled by the specialist nurse, it is evident that she too valued the opportunity to interact with young people using telehealth. The first virtual clinic was noted as 'going better than expected' and she felt 'excited' that the service is finally being offered to users. She notes her delight in being able to make an impact and see big changes to self-care practices through what she sees as 'very little input' on her part. Most young people are 'relaxed' during the virtual interaction, which helps her to feel more comfortable herself in using the technology and running a new service. It is evident that her own confidence is growing over time and she is able to adopt a range of tools to remain focused during the remote consultation, engage the users in goal-oriented interaction and set targets for the next session. She notes that a number of participants state that they are looking forward to their next Skype™ session, which for her is a proof of the value the service has.

However, the reflective diary brings to the fore the importance of having the right support mechanisms for exploring, using and embedding novel clinical practices. The specialist nurse was actively seeking guidance and technical support whilst reflecting on the challenges of being part of a small organisation, which has far less resources than those available to peers in the NHS. She was looking for clear measurements of success and compared the telehealth-mediated clinical outcomes to those which may have been achieved in a 'traditional' face-to-face paediatric clinic. Analysis of the narrative shows a clear tension between what the clinician was expecting from the technology-mediated service and what she knows is clinically achievable, given the complex health challenges faced by service users and those who support them in primary care settings.

DISCUSSION

Principal findings

Our study demonstrated that telehealth can be successfully used to extend service provision to a sample of underserved service users, with complex health care needs. The remote intervention that supported continence self-care, led by nurses and offered through Skype™, was specifically attractive for young people, some of whom preferred this mode of interaction to a consultation in a clinic. The perceived usefulness of the technology and the ease of use contributed to the acceptance of telehealth as a valued clinical tool. This, coupled with the small size and the 'can do' culture of the SSBA, resulted in a positive implementation of the service. However, the dual role and the insight that the specialist nurse had from working in both the public and the voluntary sectors added complexity to the project, which was not envisaged at the outset.

Implications of the findings

Little is known about the use of telehealth as an intervention mode for continence care amongst young people with complex needs. Our study suggests that using Skype™ to link young people to specialists helps and supports their engagement in self-care activities and gives them an opportunity to assert their role as partners in clinical decision making. The use of telehealth by a voluntary organisation, to offer virtual clinics, is an effective way to maximise limited resources and provides a flexible and user-centred service. The relative ease with which technology innovation was explored and implemented in a small and dynamic organisation had a very positive influence on extended roles for nursing staff. However, the impact on and of stakeholders from external organisations, where implementation of change to practice is at a slower pace, must be carefully considered before telehealth services are proposed.

Comparison with the literature

Our findings appear to mirror other studies – specifically those that relate to young people and the provision of remote mental health interventions. Psychiatry, as noted by Mitchel et al.¹⁰ is the speciality that made most use of telehealth in Scotland. Overall, the literature regarding telepsychiatry suggests it is a feasible, acceptable and diagnostically valid practice that serves to improve health and care outcomes. There is a growing body of evidence to suggest that for some young people, the use of telehealth might actually be the best mode of clinical assessment.⁵ It is argued that this optimal fit with mental health care practice is due to the fact that clinicians frequently use audio-visual information to aid the diagnostic and therapeutic processes. Eye contact, posture, facial expressions, body positioning and voice projection can easily be noted via telehealth, with less need for 'hands-on' examination.¹¹ These were indeed the most valued clinical feedback elements that influenced the way continence interventions were provided, at a distance. From the perspective of service users, being at home and using own technology were significant positive factors.

Accessing remote clinical expertise from home, to address a clear gap in service provision, is reported in studies that considered telehealth in palliative care for children and their families. In a recent systematic review,¹² the authors affirmed that research in this area is challenging but needed. They note that the full potential of advanced communication technologies, to serve the needs of affected families, is yet to be realised. Focusing on the UK, Kidd et al.¹³ noted that *'Telehealth is gaining widespread acceptance and is perceived to be usable and acceptable to both patients and professionals in palliative care settings'*. The virtual link to expert advice and on-going clinical interactions seem to help families to overcome the sense of isolation and assist the provision of optimal person-centred care. Our study suggests that the link to the home and the availability of experts 'in your living room' act to incentivise parents and young people to get engaged with the service and the process of setting and achieving self-care goals. However, as with other telehealth studies, Johnston et al.¹⁴ note the lack of evidence-based research, in the provision of remote palliative care. They suggest that new technology-enabled services should be an adjunct to clinical care rather than an alternative to it. Considering the complex health care needs of many young people with SB and the range of services they receive, this point is of significance to our study too.

Limitations of the method

Our study included a small sample size from a group that is already known to us as active service users. Not all those who expressed a desire to participate in the telehealth study, at the outset, were able to do so and a few young people left the study before it concluded. The data collection tool we devised and sent to participants was not effectively used. Very few questionnaires were returned to us, despite reminders given at the end of each clinical session. The evaluation was taken up by the clinical team, rather than an external investigator, a fact that may have biased results.

CONCLUSION

Our study found telehealth to be an effective means to entice young people to engage in self-care activities, relating to continence care. Demonstrable benefits were noted by parents, young people themselves and other clinicians who also care for participants in other health care settings. These were related to progress made in self-care abilities and interacting effectively with health care professionals.

Many of the technical challenges encountered by participants were easily resolved, suggesting Skype™ is an effective means for establishing telehealth services. However, support was seen as critical to the implementation of the virtual clinic. Planning for the introduction of similar nurse-led telehealth services should consider the best way to offer on-going support for clinicians who seek to engage in innovative and technology-enabled practices.

Our findings need to be seen in the context of a small study amongst a population with complex health care needs.

Further studies are needed with a larger group of young people with long-term conditions, to validate our findings. There may also be merit in extending the inclusion criteria to include young people under the age of 25 years, who remain

on a transition pathway from paediatric to adult services. The availability of specialist continence service, during the transition period, is most needed and nurse-led telehealth services can successfully support this clinical gap in service provision.

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